

National Center on Birth Defects and Developmental Disabilities Annual Report Fiscal Year 2014



Helping Children Live to the Fullest by Understanding Developmental Disabilities like Autism

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) released new data showing the estimated number of children with autism spectrum disorder continues to rise and advanced research to help us better understand "why".

More children than ever before are being diagnosed with autism spectrum disorder (ASD) making ASD an important public health concern. ASD is a developmental disability that is related to differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways. NCBDDD works to provide essential data on ASD, search for risk factors and causes of ASD, and develop resources that help identify children with ASD and other developmental disabilities as early as possible.



Accomplishments

- Shared new prevalence estimates from the Autism and Developmental Disabilities Monitoring (ADDM) Network indicating that about 1 in 68 eight-year-old children living in multiple communities in 2010 were identified with ASD. These new data can be used to promote early identification, plan for training and service needs, guide research, and inform policy so that children with ASD and their families receive the help they need.
- Promoted developmental monitoring and screening to help children with developmental delays be identified as early as possible. "Learn the Signs. Act Early" partnered with the HHS/Department of Education initiative, Birth to 5: Watch Me Thrive!, that reached federal grantees and partners in health care and child care, families, and communities across the country. Its newest tool, Watch Me! Celebrating Milestones and Sharing Concerns, is dynamic, interactive continuing education training for child care providers and teachers.
- Demonstrated the potential impact of new diagnostic criteria for ASD. Released findings from the first population-based study that suggest estimates of the number of children with ASD might be lower using the current *DSM-5* criteria than using the previous *DSM-IV-TR* criteria.
- Supported champions in communities across the United States to raise awareness of ASD and take action to help children. Disseminated an updated ADDM Network Community Report and state-specific "one-pagers". These tools offer basic information on ASD in the country and in each ADDM community, including general prevalence, differences by sex, race/ethnicity, and average age of diagnosis.
- Responded to community concerns about the number of Somali children with ASD in Minneapolis by helping the University of Minnesota implement CDC's rigorous ASD tracking method. The project findings are currently being used by community stakeholders to make improvements in the hopes that *all* children in Minneapolis are identified and connected to services and supports as soon as possible.



Looking to the Future

By working with partners across the country, NCBDDD is embedding early screening at unprecedented levels across the spectrum of services available to families and children. This action complements our research to help answer the question, “How many children have ASD?” and to document the rising rate of ASD. Our newest research expands to dive into the question of, “Why?” NCBDDD strives to discover more detailed answers to “why” and “how many,” for both children and adults. This can be accomplished by expanding our monitoring and tracking to include adolescents and adults, building our capacity beyond the ADDM network, and investigating faster and more accurate methods. Ultimately, this work allows CDC and countless organizations to better serve children and adults with ASD.

Notable 2014 Scientific Publications

CDC. Prevalence of autism spectrum disorder among children aged 8 years-Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR Surveill Summ.* 2014 Mar 28;63(2);1-21.

Bakian AV, et al. Brief Report: Independent validation of autism spectrum disorder case status in the Utah Autism and Developmental Disabilities Monitoring (ADDM) Network Site. *J Autism Dev Disord.* 2014 Jul.

Christensen DL, et al. Socioeconomic status, child enrichment factors, and cognitive performance among preschool-age children: results from the Follow-Up of Growth and Development Experiences Study. *Res Dev Disabil.* 2014 Jul;35(7):1789-801.

Johnson NL, et al. Genomics and Autism Spectrum Disorder. *J Nurs Scholarsh.* 2013 Mar;45(1):69-78. doi: 10.1111/j.1547-5069.2012.01483.x. Epub 2013 Jan 31.

Maenner MJ, et al. Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry.* 2014 Mar;71(3):292-300.

Miller JE, et al. Maternal infections during pregnancy and cerebral palsy: a population-based cohort study. *Paediatr Perinat Epidemiol.* 2013 Nov;27(6):542-52.

Phillips KL, et al. Prevalence and impact of unhealthy weight in a national sample of US adolescents with autism and other learning and behavioral disabilities. *Matern Child Health J.* 2014 Oct;18(8):1964-75.

Rice CE, et al. Screening for developmental delays among young children--National Survey of Children's Health, United States, 2007. *MMWR Surveill Summ.* 2014 Sep 12;63:27-35.

Rubenstein E, Wiggins LD, Lee LC. A review of the differences in developmental, psychiatric, and medical endophenotypes between males and females with autism spectrum disorder. *J Dev Phys Disabilities.* 2014 Aug [epub ahead of print].

Schieve LA, et al. Population attributable fractions for three perinatal risk factors for autism spectrum disorders, 2002 and 2008 Autism and Developmental Disabilities Monitoring (ADDM) Network. *Ann Epidemiol.* 2014 Apr;24(4):260-6.



Spotlight On: Association of University Centers on Disabilities

I think about my aunt often when I work with the Act Early Ambassadors and my colleagues at the Association of University Centers on Disabilities (AUCD). My aunt noticed that her son Christopher was not doing things like his older sisters. He avoided others, but he was talking and remembered stories by heart. When Christopher was about three, he was diagnosed with autism. So I was excited to have the opportunity to lead AUCD's collaboration on the pilot program of the Act Early Ambassador project (2010-2011), with ten state-level Ambassadors working to support systems for early identification of developmental delay to serve as liaisons to the national "Learn the Signs. Act Early." Campaign.

In 2014, the Ambassadors expanded to 29 states and one organization. It is rewarding to be part of the Ambassador project as I get to help develop a national network of state-level experts to improve early identification practices, as well as collaborate with campaign partners like the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). Ambassadors work as community champions with programs that serve young children and their parents, as well as health care and child care professionals to improve early identification of developmental delay. Ambassadors collaborate with state agencies and campaign partners to improve policy and programs for early identification. I have been fortunate to be able to apply the principles of action learning that I have gained through my DrPH studies at the University of Illinois at Chicago with small group examination of early identification issues and sharing of lessons learned across states so that other Ambassadors may benefit from these learnings. It is my hope that someday each state will have an Ambassador to connect parents like my aunt with vital information on childhood developmental milestones and steps to take about any concerns.

- Adriane Griffen

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